

BILL SUMMARY

H.R. 493: The Genetic Information Nondiscrimination Act of 2007

Purpose and Overview

The purpose of this legislation is to protect individuals from discrimination in health insurance and employment on the basis of genetic information. Establishing these protections will allay concerns about the potential for discrimination, encourage individuals to participate in genetic research, and take advantage of genetic testing, new technologies, and new therapies. The legislation will provide substantive protections to individuals who may suffer from genetic discrimination now and in the future. These steps are essential to fulfilling the promise of the human genome project.

Title I – Health Insurance

The legislation applies to employer-sponsored group health plans, health insurance issuers in the group and individual markets, Medigap insurance, and state and local non-federal governmental plans.

Nondiscrimination

Group Health Plan Protections: The Employee Retirement and Security Act (ERISA) currently prohibits a group health plan or health insurance issuer offering coverage in connection with a group health plan from discriminating against an individual, in the group, in setting eligibility, and premium or contribution amounts, and applying pre-existing condition exclusions to the policy based on the individual's genetic information. This legislation clarifies that genetic information includes 'information about a request for or a receipt of genetic services by an individual or family member of such individual.' It prohibits a health insurance issuer offering health coverage in connection with a group health plan from adjusting premium or contribution amounts for an entire group on the basis of genetic information concerning an individual in the group or a family member of the individual. It also restricts an issuer's collection of genetic information.

Individual Health Insurance Market Protections: This legislation prohibits health insurance issuers in the individual market from using genetic information about enrollees or their family members to adjust premium or contribution amounts, using genetic information as a condition of eligibility for insurance coverage, and applying pre-existing condition exclusions to the policy. It also restricts an issuer's collection of genetic information.

Amendments to the Internal Revenue Code: GINA allows enforcement of these prohibitions on health insurers through the use of an excise tax on group health plans that fail to comply with these rules. This same enforcement mechanism is used under present law with respect to similar health care provisions, including provisions relating to mental

health parity, limitations on pre-existing condition exclusions, the prohibition on discrimination based on health status, and the rules relating to benefits for mothers and newborns.

Medicare Supplemental Protections: This legislation prohibits an issuer of a Medicare supplemental policy from denying or conditioning the issuance of a policy, discriminating in the price of the policy, or applying pre-existing condition exclusions to the policy on the basis of genetic information. It also prohibits an issuer of a Medicare supplemental policy from requesting or requiring genetic testing and restricts an issuer's collection of genetic information.

Limitation on Genetic Testing

Group health plans, health insurance issuers in the group and individual market, and issuers of Medicare supplemental policies covered under this Title are prohibited from requesting or requiring an individual to take a genetic test. However, the legislation makes it clear that this provision does not interfere with the delivery of health care services. For instance, this provision does not limit the authority of a health care professional who is providing care to the individual to request that an individual undergo a genetic test.

Privacy and Confidentiality of Genetic Information

The HHS Standards for Privacy of Individually Identifiable Health Information (medical privacy regulations) (45 CFR Parts 160 and 164; final rule) already protect the use and disclosure of all individually-identifiable health information, including genetic information. However, a permitted 'use' of health information under the privacy rules (i.e., a specific item under 'health care operations') is underwriting, a practice that is inherently discriminatory. Therefore, this bill expressly bans the use or disclosure of genetic information for purposes of underwriting.

Enforcement

By building these protections into existing statutes (e.g., ERISA, PHSA, the Social Security Act, and the Internal Revenue Code), this Title generally uses the same mechanisms to enforce the protections established under this legislation as apply to other violations of these underlying statutes. In addition, this legislation ensures that individuals are provided the same protection under the law, regardless of whether they are currently sick or disabled, or currently healthy. All individuals (healthy and sick) have genetic information that could be used to discriminate against them.

For group health plans and health insurance issuers in the individual and group markets, the appropriate Secretary may impose penalties of \$100 per day/per person, with a minimum penalty of \$2,500--up to \$15,000 for multiple violations that are more than de minimis with an outside cap of up to \$500,000 for a violation of the protections against genetic discrimination.

With regard to the privacy provisions established by this legislation, the same enforcement structure and penalties created by the Social Security Act for the HHS privacy standards apply with regard to the privacy protections established for genetic information by this legislation. Under this legislation, the genetic privacy provisions are enforced by the HHS Office of Civil Rights. The Secretary of HHS may impose civil monetary penalties of \$100 per violation--up to

\$250,000 and 10 years in prison for violations committed for commercial advantage, personal gain, or malicious harm.

Title II – Employment Provisions

Prohibition on Discrimination

The legislation prohibits the use of genetic information in employment decisions, such as hiring, firing, job assignments, and promotions. This prohibition extends to employers, unions, employment agencies, and labor-management training programs.

Limitation on Acquisition

Employers, labor organizations, employment agencies, and joint labor-management committees are prohibited from requesting, requiring, or purchasing genetic information about an employee or family member, except for the following legitimate reasons: (1) for genetic monitoring of biological effects of toxic substances in the workplace, (2) if the employer provides genetic services, such as through a wellness program, with the employee's prior consent, or (3) for compliance with the certification provision of the Family and Medical Leave Act or its state equivalent. The purchase of commercially and publicly available documents or inadvertently requesting or requiring family medical history would not violate this title. Under each of these exceptions, however, the genetic information still could not be used or disclosed.

Confidentiality Protections

The legislation safeguards the confidentiality of genetic information in the employment setting. If an employer (acting as an employer) acquires genetic information, such information shall be treated and maintained as part of the employee's confidential medical records. Moreover, such information shall not be disclosed except in limited situations, such as to the individual or in order to comply with the certification provisions of Federal or State family and medical leave laws or a court order.

Enforcement

The legislation protects applicants or employees of employers defined under the Civil Rights Act of 1964 (42 U.S.C. 2000e(f), State employees, Federal employees, Congressional employees, and employees as defined in 3 U.S.C. 411(c)0. Claimants are required to file a charge with the appropriate enforcement agency within a certain time period, prior to filing a suit in court. The bill provides for the same compensatory and punitive damages available to prevailing plaintiffs under 42 U.S.C. 1981a, which are progressive with the size of the employer and limited to cases of disparate treatment.

Disparate Impact

The bill prohibits claims based on disparate impact and empanels a commission 6 years after enactment. The purpose of the Commission is to review the science of genetics and advise the Congress on the necessity of providing for a disparate impact cause of action in the future.

Definitions-- (Generally Apply to both Title I and Title II)

Genetic information is defined to include information about an individual's genetic tests; the genetic tests of family members of the individual; or the occurrence of a disease or disorder in family members of the individual. Genetic information does not include information about the sex or age of an individual for purposes of this legislation. A genetic test is defined as an analysis of DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes. A genetic test does not mean an analysis of (1) proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes or; (2) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved. The second exception to genetic test only applies to Title I of the legislation.

Genetic Services is defined as a genetic test, genetic counseling (including obtaining, interpreting, or assessing genetic information), or genetic education.

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